

# Recent Updates of Therapeutic Intervention Programs for Caregivers of Patient with Dementia: Proposal of Hospital-Based Individual Therapy

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Caring for people with dementia is associated with multiple devastating social, financial, physical, and psychological challenges. There is strong evidence that multicomponent tailored caregiver intervention is effective in improving caregiver well-being and delaying institutionalization. In US, the government is actively funding for developing caregiver program and to prove its efficacy through randomized controlled trials (RCTs) to translate into practice. Even with the introduction of Korean Long-term Care Plan, still, the most of the patients with dementia are being cared by the family members. The distress of caregiving is enormous, but structured therapeutic intervention program which efficacy is proven through RCT is very insufficient in Korea. The purpose of this article is to review the caregiver intervention programs of ongoing clinical trials comparing US and Korea, and to propose a tailored, therapeutic intervention program (I-CARE; A multicenter, randomized trial to assess efficacy of therapeutic intervention programs for decreasing caregiver burden in dementia caregiver) for hospital-care in Korea.

**Key Words** caregivers, people with dementia, burden, therapeutic intervention.

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## INTRODUCTION

With the increase of the aged population, the prevalence of patient with dementia (PWD) in Korea is estimated around 127 million by 2030.<sup>1</sup> The dementia care system in Korea had improved forward with the introduction of long-term care insurance, providing benefits and coverage of home-based caring and institutional care. Still, most individuals with dementia are cared by family members at home, primarily by spouses

or adult children.<sup>2</sup>

The terms 'primary' or 'informal caregiver' has been used to depict a relative who takes on the principal role of taking care of the PWD at home. Informal caregivers (CG) are often required to provide years of care and to adapt to a continuously demanding situation. Their requirements of skills are: supervising daily tasks, coping with cognitive decline, managing behavioral problems, adapting to new social and economic circumstances, and making treatment decisions. The stress associated with caring for a family member with dementia is often severe, and is associated with a heightened risk of negative health consequences and unexpected death. Caregiving for PWD are also at risk of developing mental health problems such as depression and anxiety compared to caring for

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other disease.<sup>3</sup> CG intervention programs have been developed to address these negative effects of caregiving using multi-component approaches. More than 200 dementia caregiver interventions have been tested in randomized clinical trials; they were found to be efficacious.

Compared to significant progress in development and research in Europe and North America, the situation in Korea is difficult. There is no hospital-based systematized intervention program, and there are no randomized controlled trials (RCT) to prove its efficacy. To overcome these issues and develop systematized multicomponent CG intervention program (for dementia clinic based RCT), the recent updates of CG intervention programs will be reviewed.

In the preparation of this review, literature search in Pubmed (between 2010–2016) was performed, combining the key words of ‘dementia’, ‘caregiver’, ‘intervention’, ‘randomized’, and ‘program’. This review integrated many of meta-analysis and systematic reviews currently available.

## THE FIRST RANDOMIZED CONTROLLED TRIAL

The first assessment of RCT in support of CG was in the 1990s was conducted in an Australian hospital. The CG of mild to moderate dementia of Alzheimer’s disease (AD) received a structured, residential 10-day structured training program, which started either immediately (immediate group) or with six months’ delay (wait-list group). There were follow-ups and telephone conferences over 12 months. During the 8-years of follow-up, the patients whom CG received training stayed at home longer and tended to live longer than control patients.<sup>4</sup>

## THEORETICAL MODELS UNDERLYING DEMENTIA CAREGIVER INTERVENTION

The following theoretical models were used for developing CG intervention program: the stress-coping model, the stress-management model and the cognitive behavioral therapy (CBT) model. In the stress-coping model, individuals with a stressor make two appraisals; the primary assessment is how stressful or threatening the situation is, and the secondary appraisal is the assessment of their ability to cope. Once achieved, they can employ their coping skills to new appraisals. These coping skills can include emotion-focused approaches, problem-focused strategies, and utilization of social support systems.<sup>5</sup> In the stress-management model, treatment is focused on specific aspects associated with CG’s stress, understanding

of the patient’s disease, improving management of abnormal behaviors, or using more informal and formal supports.<sup>6</sup> The CBT is a cognitive reframing, focuses on CG’s dysfunctional thoughts about PWD’s behaviors and their performance in the caring role, making them better adapted to the situation.<sup>7</sup> The CBT interventions are most structured and psycho-educational model. It targets skill training, teaching CG’s to practice self-management.

## TYPES OF DEMENTIA CAREGIVER INTERVENTION

At present, there is no accepted classification system. Developing a classification system for evidence-based treatments and care practices would involve selecting the categories and identifying factors in each category which may affect treatment and care practice outcomes. The intervention programs can be categorized into psychosocial interventions of caregiver education (multicomponent intervention, exercise training, case management, behavioral management training, skills training of individual or groups), psychosocial intervention of caregiver support (individual, group and combined individual/group supporting counseling), technology-based interventions and respite care.<sup>8</sup>

### Multicomponent interventions

The multicomponent intervention is comprised of various mixture of selection from the psychosocial intervention of CG education and support program. They can be individually-tailored treatments that are more resource intensive, such as behavior management training. A recent meta-analysis of high-quality RCTs showed the positive effect of multicomponent caregiver interventions on delaying institutionalization of PWD, addressing potential Grade A recommendations.<sup>8</sup> The rate of institutionalization decreased no less than 33% after 6–12 months of intervention compared to usual care in mild to moderately severe AD. Individualized, multicomponent interventions might reduce CG depression, and decrease the emotional pressure whilst improve the sense of burden, self-care abilities, well-being, confidence, and social support ratings.<sup>9</sup>

### Skills training

Skill-building psychoeducation is provided either on an individual basis or in a support group. The information based psychoeducation interventions include providing information about dementia caregiving, behavioral and psychological symptoms of dementia, handling daily activities, leisure education, and role transition. A recent meta-analysis on educational programs showed a moderate decreasing effect on the CG’s emo-

tional burden and a small improvement in their depression.<sup>10</sup>

### **Behavior management training**

Caregiver's emotional awareness and emotional management trainings were also used as an intervention. Two emotions, anger and depression management resulted in positive findings on negative emotion. A mindfulness-based intervention which focuses on stress awareness and its reduction is a self-management psychoeducation and has proved positive effect compared to respite control. Behavior management training augmented by CG exercise or self-care instruction resulted in broader outcome effects, improving physical mobility and coping skills. A manual-based (The START Manual: STrategies for RelaTives), individual coping intervention for dementia performed, by the therapist were effective in improving caregiver's mood and anxiety for 2 years.<sup>11</sup>

### **Caregiver support**

The CG support is an informal meeting organized either by CGs or non-medical experts to share their experiences. The most recent meta-analysis of RCTs evaluating psychosocial education and support programs found that CG support improved the CG' psychological well-being, depression, burden and social outcome than education program.<sup>12</sup>

### **Case management intervention**

Case management intervention (CMI) aims to resolve personal caregiving problems by providing individualized care. CMI includes case identification, standardized multidimensional assessment, and individualized plan, implementation of this plan, and monitoring and reassessment of the plan. PWD, who received CMI, were less likely to be admitted to a nursing home and had less agitation. However, a systematic review of the meta-analysis of CMP for PWD was inconclusive.<sup>13</sup>

### **Respite care**

There are several types of respite care: 1) Day care—planned services provided outside of the home, not involving overnight stays; 2) In-home respite services—involves a paid care worker coming into the family home to “sit” with the care recipient; 3) Institutional/overnight respite—allows one or more night's away from the family home for the PWD; 4) Video respite—a tailored video to occupy the PWD's attention, thus freeing up the CG's time for a mini-break. Respite care does offer some short-term benefits to CG, but long-term benefits such as health improvement or well-being were not different compared to control groups, or to CG's baseline state in any form of respite service.<sup>9</sup>

### **Technology-based intervention**

The technology-based interventions aimed to increase patient safety and reduce CG stress, using such as Global Positioning System (GPS) and home-monitoring devices (e.g., cooking monitors or boundary alarms). Uncontrolled studies suggest that GPS location systems may help the safety of patient's wandering behavior and reduce CG burden, but the evidence from controlled studies on the effectiveness of technology-based interventions is insufficient. Another study using psychosocial telephone intervention showed significant improvement in caregiver's depressive symptoms comparable with face-to-face intervention.<sup>14</sup>

## **DEMENTIA CAREGIVER PROGRAM AND ONGOING CLINICAL TRIALS IN US**

The National Family Caregiver Support Program (NFCSP), established by the Older Americans Act in 2000, provides a wide range of supports that assist family and CGs for their home care. The NFCSP offers five types of services: information to CG about available services, assistance to CG in gaining access to the services, individual counseling, organization of support groups, and caregiver training, respite care, and supplemental services.<sup>15</sup> The Administration on Aging mandated AD Supportive Services Program to develop new funding category devoted to translating RCT in caregiver interventions and to report peer-reviewed publications. Through this initiative, the grants were funded involving translation of five interventions: Resources for Enhancing Alzheimer's Caregiver Health II (REACH II), New York University Caregiver Intervention, Staff Training in Assisted-living Residences-Caregivers, Savvy Caregiver Program and Skills2Care.<sup>15</sup> The studies reporting translations research of five programs are summarized in Table 1. The reach, effectiveness, adoption, implementation and maintenance criteria, a broad public health model to appraise the impact of translational activities to practice can be applied.<sup>16</sup>

REACH II is a multicomponent psychosocial and behavioral training intervention for CG (21 years and older) of patients with AD or dementia which is provided in Birmingham, Memphis, Miami, Palo Alto, Philadelphia, in agencies on aging in Kentucky and Illinois and Rosalynn Carter Institutes at Georgia Southwestern State University. In this RCT, the intervention was delivered over 6 months by certified interventionists holding at least a bachelor's degree. The protocol consisted with 12 individual sessions (9 at home and 3 by telephone) and 5 structured telephone support-group sessions. The dissemination materials are on the website (REACH II Pro-

**Table 1.** Summary of ongoing Dementia Caregiver Intervention Studies in US

Citation program	Name of program	Duration	Sessions	Intervention components	Theory of translation	Study design	Reach (No. of CGs)	Effectiveness	Sustainability
Alpeter et al. <sup>17</sup>	REACH II	4–6 months	10–12	<ul style="list-style-type: none"> <li>Group support and family therapy</li> <li>Individual Psychoeducational and skill-based trainings</li> <li>Home-based environmental intervention</li> <li>Enhanced technology support systems</li> </ul>	RE-AIM	Mixed, mid-course assessment: eight-steps reviewing implementation process	15 family consultant for REACH II; 127 to 272 CGs in other studies	CG: burden, depression, risk PWD: behavioral problems	Embedded in NC Project C.A.R.E., a comprehensive dementia-specific respite program with AOA funding
Mittelman and Bartels <sup>18</sup>	New York University Caregiver Intervention (NYUCI)	4 months	4	<ul style="list-style-type: none"> <li>Individual counseling</li> <li>Family counseling</li> <li>Support group</li> <li>Ad-hoc counseling</li> </ul>	Not indicated in text	Pre-post (4, 8, and 12 months)	228 enrolled, of whom 117 (51%) had completed the minimum sessions	CG: social support, tangible assistance, reaction to BPSD PWD: depressive problems, disruptive behaviors	The State committed to continue this intervention but funding not specified
Teri et al. <sup>19</sup>	Staff Training in Assisted Living Residences-Caregivers (STAR-C)	6 months	8	<ul style="list-style-type: none"> <li>General education about disease</li> <li>ABC model of behavior change (Antecedents, Behaviors, Consequences)</li> <li>Communication skill training</li> <li>Increasing pleasant events</li> <li>Caregiver support</li> </ul>	Not indicated in text	Audiotaped sessions of STAR-C reviewed by University of Washington trainers	70 (at time of Teri et al., <sup>19</sup> 2012 Publication)	Outcome data not yet reported	Noted as an important area of inquiry for the outcome study
Samia et al. <sup>20</sup>	Maine Savvy Caregiver Program (MSCP)	6 weeks	6	<ul style="list-style-type: none"> <li>Introduction to dementing disorder</li> <li>Caregiver's self-care</li> <li>Anchors of enjoyable involvement</li> <li>Levels of thinking and performance</li> <li>Strengthening the family as a resource for caregiving</li> <li>Review and integration of the previous sections</li> </ul>	RE-AIM	Single group design, pre post, mixed-methods	770 accessed the program, of whom 676 (88%) agreed to post-test	CG's competence, situation management, keeping the PWD busy, management of more reasonable expectations, and positive aspects, depression	Integrated into two Aging and Disability Resource Centers/Agencies on Aging Family Caregiver Program
Gitlin et al. <sup>21</sup>	Skills2Care®	4 months	5	<ul style="list-style-type: none"> <li>Assessment of PWD, CG, and environment</li> <li>Introduction of prevention and management techniques</li> <li>Tailored activity program &amp; activities to effectively engage</li> <li>Stress management strategies</li> <li>Closure and apply to new problem area</li> </ul>	RE-AIM	Single group design, pre & post	41 completed one or more sessions but post-treatment surveys available for 20	Knowledge and skills (to engage PWD in activities, managing behaviors, and better self-care)	Reimbursed through Medicare B

AOA: Administration on Aging, CG: caregivers, NC Project C.A.R.E: North Carolina project caregiver alternatives to running on empty, PWD: patients with dementia, REACH II: Resources for Enhancing Alzheimer's Caregiver Health II, RE-AIM: reach, effectiveness, adoption, implementation and maintenance.

gram Web site, <http://www.edc.pitt.edu/reach2>).<sup>17</sup>

In New York University Caregiver Intervention, the 406 spouse CGs were randomly assigned to intervention or usual care control group, followed up to 18 years. It demonstrated the intervention's significant short and long-term effects on spouse CG's well-being and to avoid or postpone nursing home placement of PWD. Intervention effects were replicated in 3 Country Study in the US, UK, and Australia. It provides 6 counseling sessions (2 sessions in individual and 4 sessions in family) delivered by Bachelor's or Master's level of social worker or nurses.<sup>18</sup>

Staff Training in Assisted-living Residences-Caregivers program is a behavioral intervention designed to decrease depression and anxiety in individuals with AD and their family CG. The intervention is composed of 8 weekly in-home sessions followed by 4 monthly telephone calls. Treatment includes general education about dementia, information about the relationship between mood and pleasant events, practice identifying, and reducing behavior problems using a systematic approach (the ABC model of behavior change), training of communication skill, and caregiver support.<sup>19</sup>

The Savvy Caregiver Program is structured to train family and professional CG in the basic knowledge, skills, and attitudes needed to be an effective caregiver. The training course is delivered in 2-hour sessions over a 6-week period and can be given in other locations without program initiators. The significant positive outcomes were proven for CG who par-

ticipated in the program versus those in the control group in CG' beliefs about caregiving, reactions to the behavioral symptoms, and feelings of stress and burden.<sup>20</sup>

The Skills2Care is a randomized, controlled trial of home environmental intervention program. It is based upon a competence-environmental press framework and personal control theory. The intervention involves 5 sessions, 90-minute home visits by an occupational therapist who evaluates the home environment, observes performance of the PWD and the communication style of the CG. Based on this assessment, the interventionist provides basic education and trains CGs to develop strategies to cope with daily care challenges. The Strategies are simple modifications to the physical environment (e.g., removal of hazardous objects, use of a memory board or daily calendar) and social environment (e.g., communication techniques, cueing and approaches to simplifying everyday tasks) to more resource dependent recommendations (e.g., installing grab bars or handrails).<sup>21</sup>

## DEMENTIA CAREGIVER PROGRAM IN KOREA

There are several dementia caregiver programs in Korea which were developed for public communities such as regional Center for Dementia, day-care center or welfare centers. These are Dementia Caregiver Support program from the Korean Association for Dementia, Cognitive-behavioral therapy

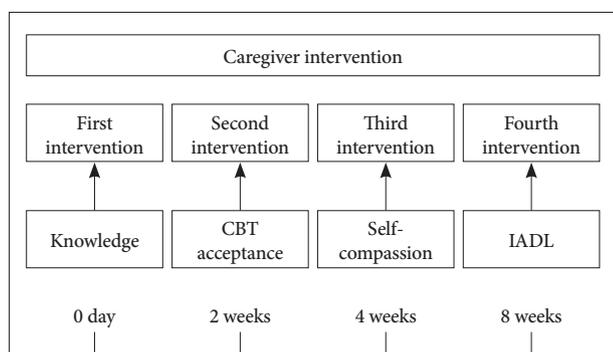
**Table 2.** Summary of dementia caregiver intervention program in Korea

Principal investigator, year	Name of program	Duration	Study design	Number of session	Intervention components
Korean Association for Dementia, 2013	Caregiver of dementia supportive program	6 weeks	No provided data	6	Dementia understanding Self-curing Communication Living happily with dementia Living well with dementia Future planning
Lee et al., <sup>22</sup> 2013	Cognitive-Behavioral Program for Care-givers of the elderly with Dementia: Preliminary study	4+8 weeks	Controlled study pre-post test	4+1	Relaxation Cognitive Model education Spontaneous thinking Substitutive thing Practice and application
Park et al., <sup>23</sup> 2015	Multimodal Psychoeducational Program	8 weeks	Non-equivalent control group pre-post test	8	Orientation Taking care of the patients with dementia Taking care of myself Managing safety Living with happy life with elder with dementia Looking for hope within family Looking for resources Wrap up

program<sup>22</sup> and multimodal psychoeducational programs (Table 2).<sup>23</sup> Additionally, the Rosalynn Carter Institute for Caregiving Korea established in 2010, provides specialized caregiver educational programs. Nevertheless, these programs are designed for group intervention in the public community setting, and no RCT evidence is available to prove the competence of the program.

## DESIGNING OF TAILORED MULTICOMPONENT HOSPITAL BASED CAREGIVER PROGRAM IN KOREA

A multicenter, randomized trial to assess efficacy of thera-



**Fig. 1.** I-CARE. CBT: cognitive behavioral therapy, I-CARE: Intervention program for CAREgivers of patient with dementia, IADL: Instrumental Activities of Daily Living.

peutic intervention programs for decreasing CAREgiver burden in dementia caregiver (I-CARE) is being conducted in 9 hospital-based dementia clinic (Bobath Hospital, Pusan National University Hospital, Chuncheon Sacred Heart Hospital, Dongtan Sacred Heart Hospital, Ewha Womans University Mokdong Hospital, Hallym University Sacred Heart Hospital, Inha University Hospital, Myongji Hospital, and Seoul Asan Hospital). This clinical trial is funded by National Evidence-Based Healthcare Collaborating Agency. I-CARE is composed of 4 sessions: one group education delivered by physician and 3 individual sessions delivered by clinical neuropsychologist trained in psychotherapy (Fig. 1). It was designed to compose caregiver education (group education lecture with caregiver support), CBT (behavior management training), stress-coping (self-compassion and acceptance) and stress-management (skill management). First session of group education is focused on delivering information and free discussion for each caregiver. Individual sessions were focused on caregiver to 1) recognize and understand behavioral problem of PWD, 2) self-appraisal of their effort and how to overcome stress, and 3) simple skill buildings that caregiver can do with PWD (Table 3). Primary outcome is improvement in Zaret's Burden Inventory and Philadelphia Geriatric Center for Moral Scale. Secondary outcome is any change in Caregiver-Administered Neuropsychiatric Inventory, Instrumental Activities of Daily Living, Geriatric Depression Scale, Acceptance & Action Questionnaire, Self-Compassion Scale and Positive Affect

**Table 3.** Detailed intervention contents of I-CARE

Contents of session	Intervention type	Interventionist	Theoretical model	Intervention component
1st (knowing dementia)	Group education	Physician	Education	Dementia Education & understanding Diagnosis of dementia Treatment of dementia Symptoms of dementia & approach in disease course
2nd (understanding behavioral problems in dementia)	1:1 (individual session)	Neuropsychologist	Cognitive behavioral therapy (behavioral management training & acceptance)	Recognition of BPSD in individual patient Assessment of BPSD induced caregiver's stress Analysis of BPSD induced caregiver's thoughts & emotion Analysis of previously applied method Appraisal of CBT to BPSD related negative emotion Acceptance of BPSD
3rd (self-efficacy & confidence)	1:1 (individual session)	Neuropsychologist	Stress-coping model (acceptance & self-compassion)	Analysis of previous coping strategies for stress Development of new coping strategies with problem-focused strategies with self-compassion
4th (maintenance of daily activities)	1:1 (individual session)	Neuropsychologist	Stress-management model	Skill-building psychoeducation using I-CARE calendar Medication persistence and management skills Personal item management skills Daily schedule management skills

BPSD: behavioral and psychological symptoms of dementia, CBT: cognitive behavioral therapy, I-CARE: Intervention program for CAREgivers of patient with dementia.

and Negative Affect scale. I-CARE RCT is currently ongoing, targeting 98 CG of AD (CG distress score  $\geq 2$ ) and expected to finalize end of 2016.

## CONCLUSION

There has been emerging evidence in recent years demonstrating that interventions targeting the patient's basic support, external environment, physical, cognitive and psychosocial activity are effective. In addition to patient-centered approaches, the convincing evidence indicates the efficacy of caregiver-centered multicomponent interventions in the mild to moderate dementia stage. It decreases caregiver burden, increases positive emotion and even delays institutionalization. Eventually, a need for developing an integrative multicomponent intervention that brings cognitive, psychosocial and physical strategies for each stage of dementia (especially for mild to moderate dementia) adapted to the practical needs are paramount. If CG intervention could start in the early stage of disease, it may help CG in accepting and planning the future through developing. Also, an education of advanced dementia CG showed a reduction in agitation and anxiety in dementia and enhanced the end-of-life care (e.g., decisions on hospitalization, antibiotics or percutaneous endoscopic gastroscopy).<sup>24</sup> Evidence from end-of-life studies, it prevented pathological mourning of caregiver after the patients' death.<sup>25</sup> Hence, with this paramount evidence, dementia wards and memory clinics should integrate caregiver education and support activities into therapeutic CG intervention concepts.

To incorporate CG intervention program to practice, there are two main obstacles. The major problem is the lack of remuneration in the implementation of caregiver by national health insurances. The 2014 World Alzheimer's Report concluded that even with CG multicomponent interventions with proven its efficacy, no governments have invested in this intervention to scale-up provision throughout the dementia care system. The Korean Ministry of Health and Welfare announced that dementia caregiver program will be reimbursed in the mid of 2016, but no further administrative action is being taken. Another problem is, there should be more scientific proven CG intervention program in wide range of focus. Advancing translational efforts will require the greater investment of government funds, and thus inserting translation and widespread implementation from policy makers and service providers. Through this process, the principles shared by proven interventions will be identified, and the guidelines and best practices will emerge. Guidelines will be useful to service providers which typically require specialized training, fidelity monitoring, and on-going researcher involvement.<sup>26</sup> Given

only a few treatments available in an epidemic of dementia, attention to family CGs incorporating non-pharmacological treatment and CG intervention program into practice is a medical and public health imperative.

### Conflicts of Interest

The authors have no financial conflicts of interest.

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